



Health Information Exchanges: Similarities and Differences
HIMSS HIE Common Practices Survey Results White Paper

**HIMSS Health Information Exchange
Best Practices Task Force**

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Executive Summary

The HIMSS Health Information Exchange (HIE) Best Practices Task Force spearheaded the 2008 HIMSS HIE Common Practices Survey for the purpose of gaining insight into practices common to HIEs operating today in the United States. For purposes of this survey and white paper the HIMSS HIE Best Practices Task Force screened out HIE organizations that appeared to be in the planning and early development stages. Only operational HIE organizations or those entities actively exchanging data were targeted for completion of the survey. Twenty-one HIE organizations completed the survey in 2008 and agreed to participate in this project. While the actual total number of HIE organizations actively exchanging information is not clearly identified in the industry, it is believed that the twenty-one participants did represent a significant number of these HIE entities at the time of the survey administration. This white paper presents the findings from the survey as reported by the survey participants and is not intended to represent all HIE organizations.

All of the twenty-one HIE organizations that participated in this survey have been actively exchanging data in at least a pilot mode for a minimum of six months. The survey covered the period from the formation of the organization through the active exchange of data. The survey included questions regarding key stakeholders, funding sources (initial and ongoing) and the technical architecture deployed by the HIE. A unique feature of the survey is the in-depth focus on technical topics including standards deployment, integration/interoperability, privacy/security, common application set, software and service level agreements.

Principal Findings

- **Belief in Uniqueness** – Even though the HIE organizations surveyed are similar in purpose and formation, it appears that most did not follow a model or guide during formation. This was due to a belief in the uniqueness of their resources, regions and charter. Nevertheless, the survey results indicate several commonalities in both administrative and technical areas that could be worthy of further in-depth research.
- **Physicians, Health System Primary Stakeholders** – The stakeholders that are initially and currently engaged at most HIEs appeared to be health systems, primary care physicians and specialty care physicians.
- **Membership Model Linked to Sustainable Funding** – All of the respondents who indicated having sustainable funding use a membership model.
- **Government Grants/Other Beneficial Funding Key to Survival** – Sixty one percent of survey participants expressed a dependency on grants and contracts for long term sustainability.
- **Buy Rather Than Build** – Seventy one percent of the respondents stated that their HIE chose to buy rather than build the actual technical exchange and its primary applications.
- **Vendor-Hosted Exchanges Predominant** – Seventy one percent of the respondents have data exchange activities operating from a hosted source rather than at their own facilities. Most respondents appear to use the primary vendor as the hosted source.

- **No Fully Federated HIEs Identified** – Most of the responding HIEs reflected having either a hybrid or federated architecture.
- **Service Oriented Architectures Common** – Service oriented architecture (SOA) is used by sixty one percent of the respondents.
- **HIEs Support Common Standards:**
 - **Messaging Standards** – ninety percent of the respondents support HL7;
 - **Data Standards** - Most HIEs support one or more of the common health industry data standards such as ICD-9, CPT-4, LOINC-1 and NDC.
- **Adopt Data Transformation Strategies** – The participants indicated that the two data transformation strategies used most often are “normalization and encoding” and “data mapping/translation” – language normalization was also reported by several of the HIEs.
- **Bi-Directional Exchange Availability** – Bi-directional data exchanges were indicated to be occurring in seventy one percent of the respondents, and the remainder are planning on a bi-directional exchange in the future.¹
- **Lab Results, Prescriptions Top Functions** – Data most often exchanged for inpatient, outpatient, and physician practice office include lab results and prescriptions. Clinical patient notes and documentation are also noted in the survey as being exchanged between inpatient and outpatient settings.
- **Opt-In, Opt-Out Provisions Common** – Sixty percent of the HIE respondents allow for patient opt in or opt out.
- **Interoperability Concern for Most** – Eighty five percent of the participants indicated they have considered interoperability with other HIE organizations at the state or federal level.

Methodology

The HIMSS HIE Best Practices Task Force developed an in depth survey tool for the purpose of determining if common practices across HIE organizations could be identified. The HIMSS HIE Common Practices Survey was administered during spring, summer and fall of 2008 utilizing primarily an online survey tool. The HIE Best Practices Task Force compiled a list of HIEs from several industry listings that were reported as existing or having existed during this time period. Out of this initial listing, investigation efforts determined that some organizations were no longer in existence and many were in a formative stage. After these HIEs were eliminated from this initial list, a target contact list was identified of those HIE organizations believed to be actively exchanging data. The Task Force reached out to those HIEs by email and telephone inviting them to participate in the survey. The result of this outreach effort was that twenty-one (21) HIE organizations completed the HIMSS HIE Common Practices Survey through either the Web-based survey tool or using the Microsoft Word version of the survey. This report reflects the information as reported in the survey by these HIE organization participants. There was no

¹ It must be noted that all but two of the participants reported use of portals. It is concluded for this study’s purpose that the “bi-directional” question was interpreted as indentifying bi-lateral exchange based on a portal that integrates data from multiple sources rather than an actual integration/interface of data between participant systems. This should be a subject of further research and or follow-up in future surveys.

additional follow-up with the twenty one (21) participants after they submitted their completed surveys. The survey results are summarized in this report divided by content sections which follow the sections of the survey questionnaire. These content sections include:

- Respondents Overview
- HIE History
- HIE Initiation
- Organizational Overview
- Technical Overview
- Interoperability Overview

Appendix A contains the Microsoft Word format of the survey used in this project.

Respondents Overview

Survey Questions 1, 2, 4, 7-8

The twenty one (21) HIE organizations that responded to the survey represent 16 states nationwide. These HIEs were formed between 1993 and 2008. Six (6) of the HIEs are exchanging data in pilot mode only. Ninety percent (90%) of these HIE organizations indicated they are non-profit.

Eighty percent (80%) of the survey respondents represent a job position level of Director. Other respondents hold the position of Chief Medical Officer, Chief Operating Officer, Vice President, and Project Manager. The level of involvement by these respondents within their HIE organizations made them suitable for completing the survey.

HIE History

Survey Questions 7-8, 23

Some of the responding HIEs started out during the early 1990s as Community Health Information Networks (CHINs). These CHINs evolved into Regional Health Information Organizations (RHIOs) during the early to mid 2000s. There has been a steady increase in development of HIE organizations and initiatives within various regions of the country from the early 2000s to the present. Even with only twenty-one (21) participants, the survey results reflect this evolution as twenty-nine percent (29%) of the participating HIE organizations started during the 1990s while seventy-one percent (71%) of these HIEs were started during the 2000s. It should be noted that all twenty one survey participants are currently in operation.

HIE Initiation

Survey Questions 6, 7-10, 12-13, 17, 30-31

HIE Type & Purpose

The HIEs that responded stated that ninety percent (90%) are non-profit organizations. Sixty-seven percent (67%) of these non-profit organizations are either a designated 501(c)(3) or in the application process for becoming a designated 501(c)(3). The initial drivers and stated purposes for formation of the participating HIEs varied widely, but typically included statements such as:

- Improving the quality of healthcare
- Improving patient safety
- Reducing care inefficiencies through better information availability
- Promoting and protecting the health of the community
- Improving the satisfaction of patients and providers with the healthcare delivery system.

Many respondents also cited rising healthcare costs, community and state initiatives, and reduction of paper as drivers for their formation. These value-driven purpose statements have also been reiterated through the examination of other HIE organizations' Web sites and with literature research beyond the twenty-one (21) HIE survey participants.

HIE Community

Most of the HIE participants indicated they were formed as a collaboration of stakeholders within a geographic community rather than by a single provider, payer or vendor/consultant. Sixty-seven percent (67%) of the survey respondents chose "community initiated" (Figure 1), an indication that the HIE entity was convened by organizations with a set of common goals covering a particular service area or geographic focus.

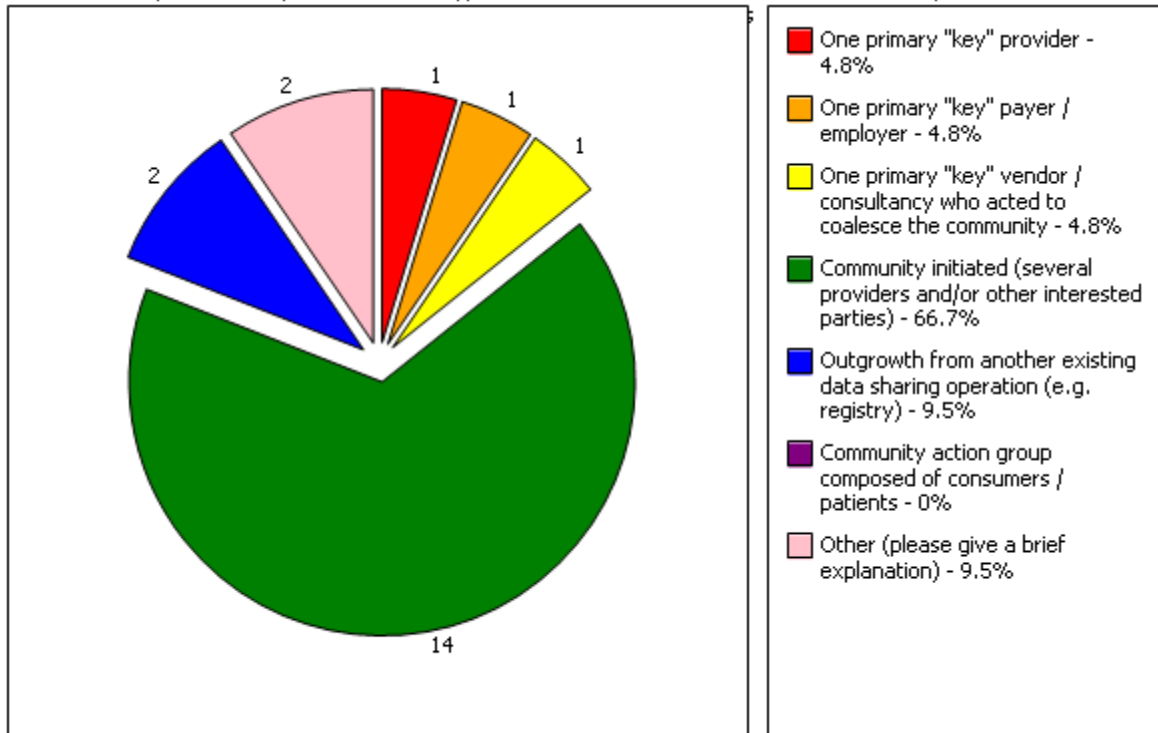


Figure 1. How HIEs Participants Were Initiated

Start-up Documentation

Start-up organizations typically develop charters, capital budgets, operating budgets, business cases, funding models and other key management documentation during their formation. These foundational documents provide necessary information about the costs of starting the HIE as well as the vision and value of the HIE. The survey responses indicated that only sixty percent (60%) of the HIEs responding created capital and operating budgets and secured independent start-up funding prior to initiation. Even for an emerging market and a small number of survey participants, this is a surprising result since it could reflect that forty percent (40%) appeared not to have documented their long-term viability strategy as part of their initial charters and entity formation.

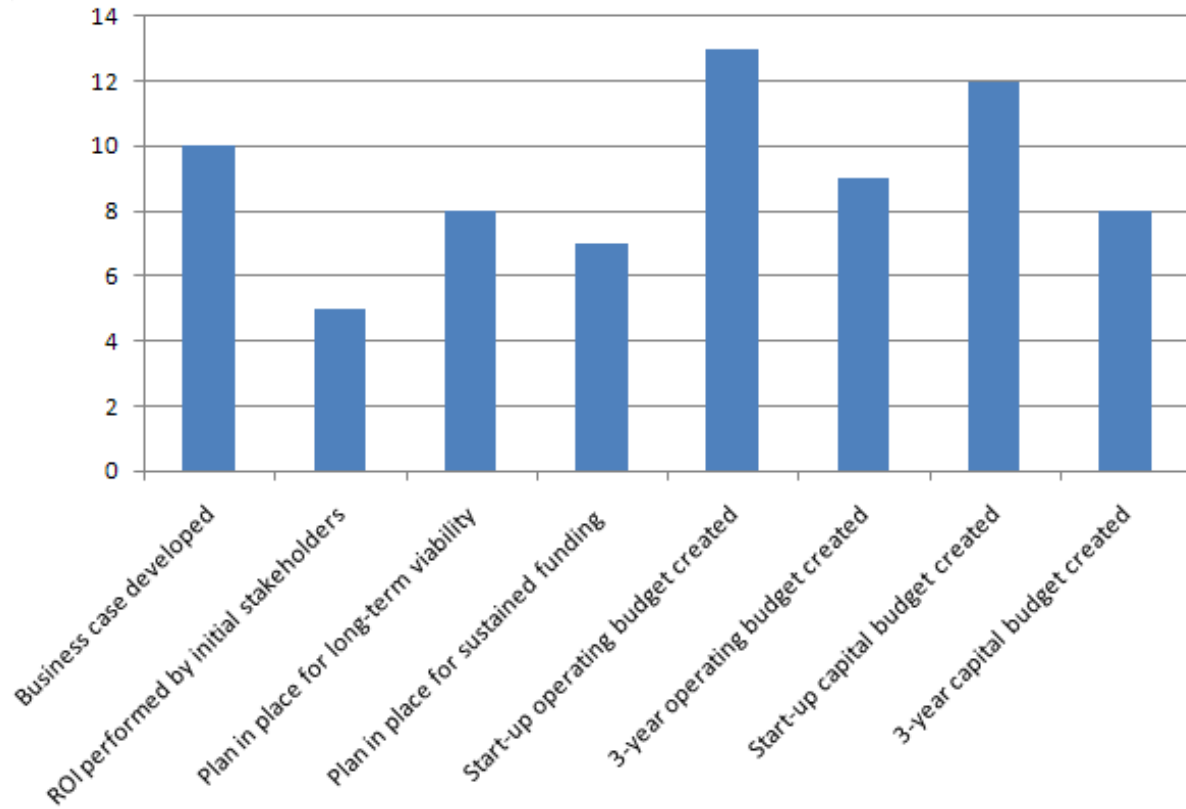


Figure 2. Documents Completed Prior to HIE Start-up

Services

A common goal of HIE communities is to facilitate sharing of information (exchange of data) among HIE participants which is reflected in their planned initial service offerings. The exchange of data and provision of Master Patient Index (MPI) patient locator services were most frequently cited as planned initial services by our survey participants, followed by user authentication/authorization, results delivery, and registry.

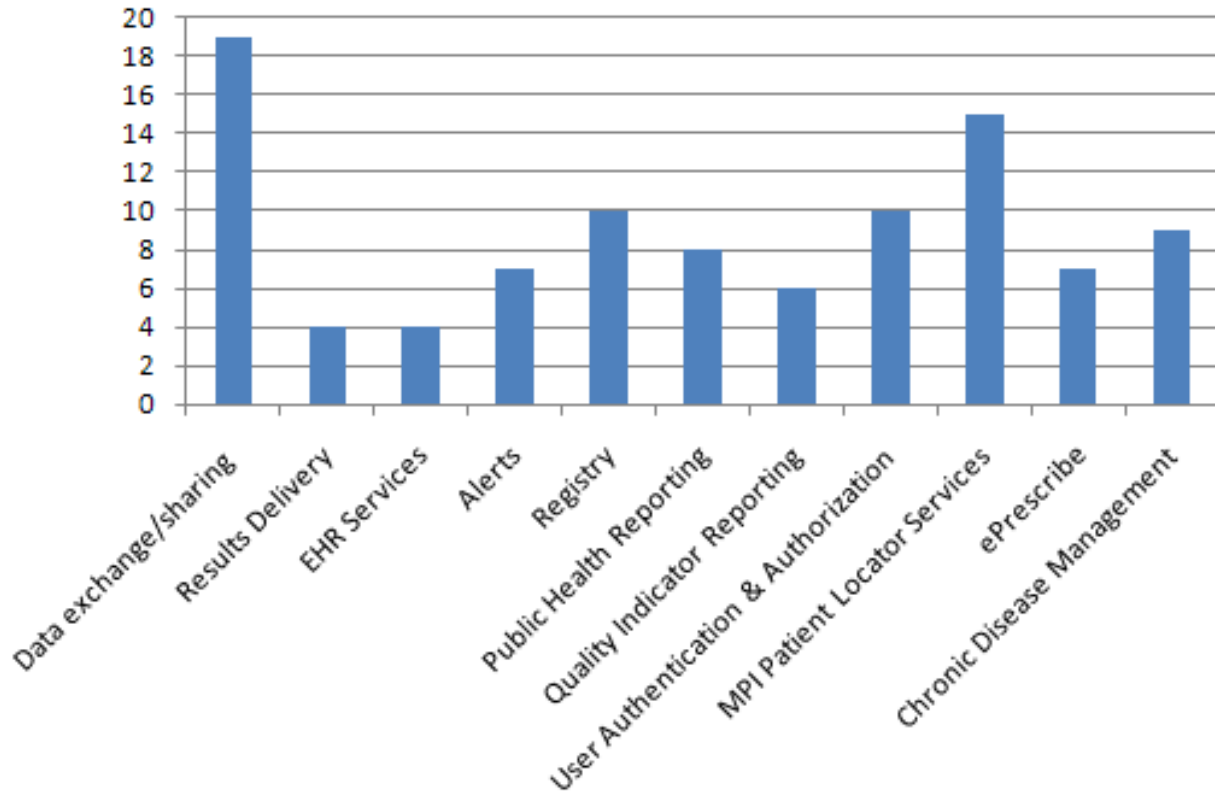


Figure 3. Planned Initial Service Offerings

Uniqueness

Although there are many similarities in how HIEs are established, most of the HIE participants did not pattern their organizations after another HIE nor did they follow any guide to creating their HIE. Eighty-one percent (81%) of the survey respondents did not model their implementation after another HIE. Ninety percent (90%) of the responding HIEs indicated that no pre-established implementation guide was used.

Even though each of the HIEs in the reported sample maintained that they were unique, their start-up funding/entities, organizational structure and technical architecture appear remarkably similar. This would indicate, if corroborated by further research and investigation, that a common set of guidelines could possibly be developed for organization structures, implementations, and technical architecture frameworks and prove valuable to the HIE community. Additional research is required to substantiate this finding.

Organization Overview

Governance

Organizational Structure

Survey Question 11

All of the respondents reflected HIE organizational structures that incorporate stakeholder and community members within their leadership. Seven (7) of the HIEs have boards that include members from a variety of participating organization types. Five (5) HIEs have executives on their boards who come from their stakeholder organizations, reflecting a high level of commitment to these nascent exchanges. Some of the participants indicated having management committees (e.g., executive and steering committees) made up of stakeholder appointees and community volunteers.

Stakeholders

Survey Questions 14- 16, 18-20, 25

Based on the survey results, the initial entity stakeholders provided the impetus, credibility and authority to the HIE organization throughout the start-up and the transition to production with an operational HIE. Stakeholder involvement appeared to increase as the organization went through the various development stages of start-up (provided start-up funding), transition (initially involved), and production (currently involved). There is not enough information from the survey results to identify why the number of stakeholder participants increased as the HIE entity developed. This increase in stakeholders could potentially be due to several factors ranging from successful initiation of data exchange, to an increase in breadth of data exchanged, to increased functionality of the more mature HIE. Most of the HIEs appeared to have begun with hospitals, primary care physicians, and specialty care physicians as a core group of stakeholders which have continued their participation throughout all stages of maturation. Most often it appeared that these stakeholders also provided start-up funding to the HIEs.

Hospitals, specialty care physicians, private payer/health plans, and primary care physicians appeared to be the top four (4) stakeholders during start-up (Figure 3). Fifty-seven percent (57%) of the participating HIEs have a hospital as a stakeholder who provided start-up funding. Specialty care physicians and private payer/health plans provided start-up funding at thirty-eight percent (38%) of the HIEs. Primary care physicians also provided start-up funding for thirty-three percent (33%) of the HIEs. The stakeholders that are initially and currently engaged at most of the participating HIEs are primary care physicians, hospitals, and specialty care physicians (Figure 4).

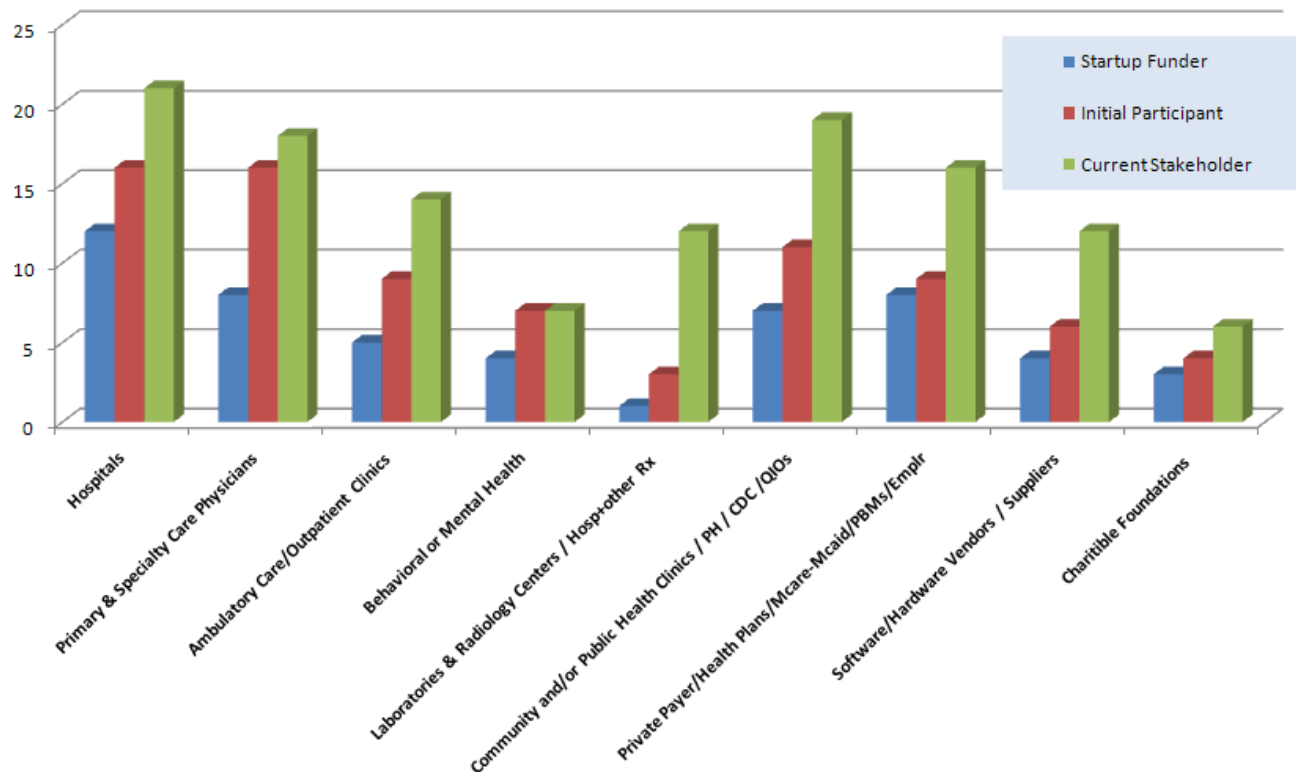


Figure 4. Stakeholders

Inclusive Nature of Initial Organizations

Eighty-one percent (81%) of the HIEs responded that no stakeholder was deliberately excluded from the organization. Four (4) HIEs did reject specific stakeholders excluding vendors, social organizations or payers. One of these HIEs stated that the reason for excluding certain stakeholders was to maintain focus on improving clinical data.

Participant Agreements and Service Contracts

Participant agreements establish the guiding principles around data exchange and protection agreements between the participating organizations within the HIEs. Eighty-one percent (81%) of the HIEs used participant agreements with their stakeholders. Other agreements are used by the participating HIEs such as service contracts specifying services and technology that are provided, subscription agreements, and data use agreements specifying privacy and security for the data usage and data sources.

Leadership – Transitions from Initiation to Maturity

Survey results reflect that the lead organization in the HIE entity varies from the HIE itself to specific medical centers or other interested funders. In a few cases, the lead organization changed as the HIE matured, transitioning from the convener (Medical Center or Payor) to a

more community-based form of HIE governance. Organizational oversight in mature organizations is still performed by the participating entities fifty-seven percent (57%) of the time.

Finance

Survey Questions 21-22, 26, 27-29, 76- 77

Funding Sources – Grants, In-Kind Services and Recurring Subscription Fees

Sixty-one percent (61%) of the HIE respondents indicated having grants or contracts from the government and/or in-kind resources as funding sources. In-kind resources include services, equipment, personnel on loan, and other non-cash resources that are contributed to the HIEs. Forty-three percent (43%) of the participating HIEs indicated having funding sources from recurring subscription-based fees. Continuing financial contributions such as donations and grants are a part of thirty-nine percent (39%) of the respondents' funding sources.

Membership Model – Basic and Subscription Fees

Forty-eight percent (48%) of the respondents indicated they use a membership model for sustainable funding. The membership model generates revenue from a basic membership fee upon joining the HIE and a subscription fee on a monthly or annual basis. These membership and subscription fees are based on the type (hospital, insurance, and government) and size (number of physicians, number of beds, and number of patients) of the organization.

Dependence on Grants and Donations

Even though many respondents appear to have a membership model of some kind as a funding source, seventy-one percent (71%) of the HIEs indicated they are also dependent upon grants or other beneficial funding. They also indicated that they most likely would not be able to survive beyond twelve (12) months if this additional funding was removed. The average amount of time that these HIEs indicated they would survive without this additional funding is almost six (6) months. The remaining seven (7) HIEs participants responded that they would be able to survive long term without this funding source because they have a sustainable business model that is not dependent upon grants.

Operational Funding

The survey respondents indicated that operational funding is used for salaries/wages/benefits, consultants/contractors, vendors, office materials and supplies. All of the respondents indicated that the HIE manager is a paid individual who may be an employee or a consultant. Unlike many of the other HIE positions, the HIE managers are not volunteers. Travel is another important part of operational funding because so many different organizations are a part of the HIE.

Benefits Realization / ROI

Sixty-three percent (63%) of the respondents indicated they have measurements to determine return on investment (ROI) and/or benefits realized from the data exchange function. The types of measurement vary and include:

- Collection of data on the economic value of avoided errors
- Reduction in duplication of tests; reduction in hospitalizations due to improved medication management
- Reduction in visits through better chronic disease management
- Measurement of clinical data availability for a patient's transition of care within a physician and health system network

This is an area which would benefit from further research and documentation with a focus on the methodology and metrics that demonstrate benefits to the entire HIE community nationally.

Technical overview

Service Levels

Service levels can be stated and contracted in many ways; from application response times to support desk response and HIE up-time availability. Nine (9) responders indicated they have service level expectations. For those with service level expectations, the response time service levels ranged from a few seconds to a standard Web response. The response time was anywhere from three (3) seconds to within one (1) working day with the assumption that the one (1) day was for trouble resolution. Support and training for participants was also mentioned, and for those that did, it was usually available online, 24/7.

Architecture

Survey Questions 41-42, 46, 49-51, 55-57

The survey results show that eighty-six percent (86%) of the respondents considered the system architecture before the HIE entity was organized. However, forty-two percent (42%) of the HIEs indicated that the technical architecture was a direct result of the vendor selected. It can only be assumed that consideration of the system architecture may have influenced the final choice of vendor, but actual survey results do not support this conclusion.

In general terms, Regional Health Information Organizations (RHIOs) and HIEs can be said to have one of three architectures: centralized, federated (or decentralized), and hybrid.

- A **centralized model** has organizations sending patient demographic and clinical information to a shared repository. This centralized repository is queried to obtain a patient’s clinical results and other information.
- A **federated model** allows the data source organization to maintain custodianship and control over the patient’s medical record and indices. When requested, data is queried from the data source organization.
- A **hybrid model** is a mixture of the federated and centralized models.

The architecture expressed in the survey results by fifty-seven percent (57%) of the respondents was federated and thirty-three percent (33%) of the respondents stated that they use a centralized architecture. One respondent stated that their HIE is a hybrid. Further examination of the architectural section results indicate that virtually all of the organizations that indicated they are “federated” actually may use some combination of centralized components. This could lead to identifying these HIEs as using a hybrid model. Survey question responses that supported this conclusion reflected the use of centralized access management/centralized patient indexes. Of the twelve (12) organizations identifying as federated, six (6) claimed to have a centralized repository, ten (10) indicated having a centralized MPI, and eleven (11) indicated using a centralized user registry – all of these architectural components typically are distributed in a fully federated model. The survey results indicate that this is an area for additional investigation and research in the future.

Service-oriented architecture (SOA) is used by fifty-two percent (52%) of the respondents. SOA is a method for system development where functionality is grouped by business process and those business process components (“services”) are developed and hosted independent of each other. These “services” are then flexibly linked together into applications through defined workflows. Since a federated architecture requires SOA, it is not surprising that the number of participating HIEs indicating use of SOA closely corresponds to the number of HIEs identifying themselves as federated. The use of SOA varies from authentication to decision support. In general, some older HIE entities may not be able to support SOA due to the age of their architecture platform which may not be SOA-compatible.

Most of the responding HIEs indicated having systems with the following “services”:

- Transaction log
- Portal for authorized viewing of data
- Central patient index
- Central registry of users

Many indicated supporting clinical repositories (Figure 5). All of these elements are used for the exchange of data, and the transaction logs are required by HIPAA regulations.

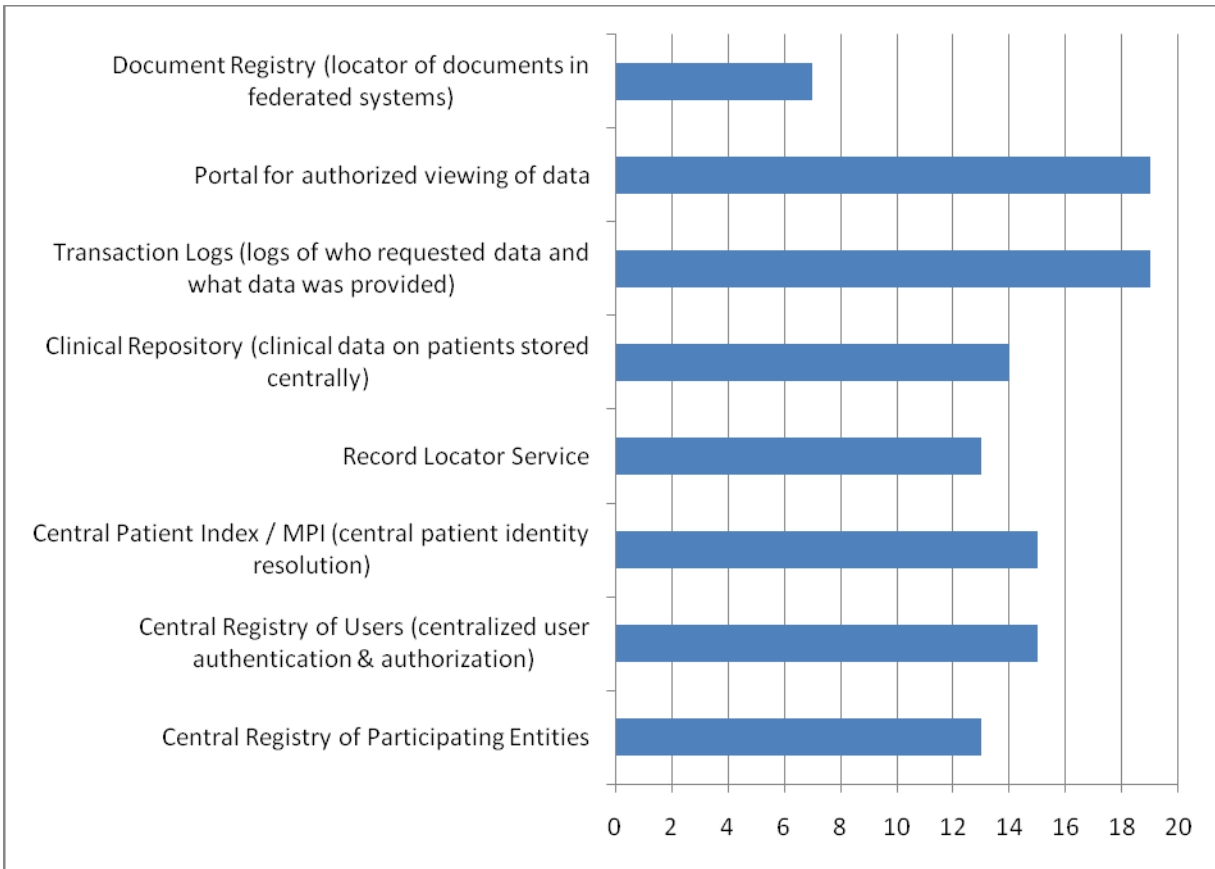


Figure 5. HIE System Architectural Elements

Physical Infrastructure

Survey Question 43-44, 47

Seventy-one percent (71%) of the respondents indicated having data exchange activities operating from a hosted source rather than at their own facility. Most of the respondents list their primary vendor as the hosted source. This leads to the conclusion that while some of the centralized services are hosted at the HIE sites, the majority of services are either fully or partially outsourced. Also, the software vendors are often the chosen partner. The choice of vendor not only leads to the architecture chosen but also may lead to the type of infrastructure provided as well.

A side observation of the survey results is that several of those who indicated having some services within the HIE itself are the older HIEs. The survey tool did not include a question asking whether or not the choice to host those services was simply because an outsourced solution did not exist at the time of vendor selection. The newer HIEs appear to have mostly chosen to go with an outsourced approach which may have something to do with the HIEs' business drivers. For example, several of the participants indicated in other comments in the

survey that they are or were part of the NHIN pilots, or were funded to accomplish a specific set of data exchange requirements, and that there was/is significant pressure to get applications running to demonstrate utility.

Ninety-one percent (91%) of the respondents require Internet access by the end user. Fifty-seven percent (57%) of the respondents indicated that the end user's access to the HIE portal is through virtual private network (VPN) access. This leads to an assumption that the remaining respondents may use some form of secure sockets layer (SSL) tunneling (Https) since this use of Web access must be secured. Therefore, it appears that most of the participating HIEs provide data to their users through some form of portal access, regardless of what other system-to-system exchange is also hosted.

Business continuity can be simply described as the process for continuing business operations in the event of failures. Failures may be many types including a natural disaster such as a hurricane that immobilizes the infrastructure in significant sections of the country (Katrina, for example). The purpose of asking survey questions about business continuity is to gain an understanding of the physical and technical security controls deployed to keep the exchange in operation regardless of the outage event. Most of the responding HIEs have all or a combination of the business continuity features including storage area networks, disaster recovery sites, mirrored/RAID disk architecture, virtualized/high availability servers and hot-failover servers to maintain a high level of exchange availability. Because one of the key benefits attributed to HIEs is the availability of data in emergency or disaster situations, clearly the deployment of a solid business continuity strategy is important to HIEs.

Application

Survey Questions 52-54, 58

The survey addressed the source of software for HIE organizations – buy vs. build. Seventy-one percent (71%) of the respondents stated that their organization chose to buy rather than build their software application. Most common reasons provided for purchasing software were lower cost and faster implementation time. One respondent added that the purchased product has better scalability. Another respondent shared the philosophy of “buy where possible, develop when necessary.” The predominant reasons expressed by the participants for developing their software included the following:

- Development site for the vendor
- Nothing available at the time the HIE started, or with extremely tight budgets
- The use of open source products coupled with limited development allowed their operation to survive and continue adding features (Rural Safety-Net HIE)

Open source software solutions are found deployed within HIE environments more today than ever before. There are a growing number of services that can be obtained from open source suppliers at minimal or no charge, but implementation and maintenance expertise may be perceived as problematic. The survey focused on identifying those entities that actually investigated and ultimately chose to deploy open source. Thirty-three percent (33%) of the respondents indicated that they used open source products as part of the HIE deployment; however, most of that software was of an infrastructure nature (Linux, Apache Tomcat, Postgress, Open-SQL products, OpenESP, Nagios.) Only two (2) respondents cited use of an open source HIE software component (MIRTH HL7 Engine.) Most respondents that used vendor packages indicated “No” to the “Open Source” survey question; however, in many of those cases, the indicated vendors are also known to use some open source infrastructure components.

Data Management and Standards

Survey Questions 67-73, 69

Many HIE organizations use standards to facilitate sending data, transforming data, and the storage of data. All survey participants indicated they were using data standards in some manner.

HL7 messaging standards appear to be supported by ninety percent (90%) of the respondents. The Health Level 7 (HL7) transaction standards coupled with IHE implementation profiles (www.ihe.net) are key significant strategies in the healthcare industry for exchange, integration, and sharing of electronic health information. Fifty percent (50%) of the HIEs surveyed use National Council for Prescription Drug Program (NCPDP) standards for communicating pharmacy claim information. Forty-five percent (45%) of the respondents indicated the use of Digital Imaging and Communications (DICOM) standard for handling, storing, printing and transmitting medical images. Accredited Standards Committee (ASC) X12, an electronic data interchange standard, is also used by forty-five percent (45%) of the respondents, primarily for communication of claims data. Two (2) respondents stated that DICOM and HL7 are not currently supported in their organization but planned for the future.

Eight strategies for data transformation were listed in the survey tool, and of those, the two strategies identified most often are “normalization and encoding” and “data mapping/translation (Figure 5).” Based on survey results, it appears both of these strategies were most always selected together.

Normalization and encoding is a process of scrubbing the inbound data against a standard template which can “normalize” data (make it conform to a specified format and data content). For example, if temperature data is stored using the Celsius scale but the data comes in

Fahrenheit, the data would be converted to Centigrade. Data mapping/translation is a more simplistic process that maps data from one interface format to another or to an internal storage format with the ability to translate values as needed (e.g., Male = M = 1; Female = F = 2). This is the most typical data management technique used before data is stored in a central repository or displayed.

“Communication and display” (a technique used in federated models where the data is gathered from source applications “on the fly,” normalized, and then populated into a portal) was cited as being used by sixty-nine percent (69%) of the respondents for data transformation. This response is surprising since the technique is relatively new. However, it is being evaluated in two of the NHIN pilots. Eight (8) respondents indicated that they use this data management technique, but clearly this response does not correlate with the responses indicating use of centralized databases. One legitimate interpretation of this result could be that many respondents store the data separately, and then merge it at the time of portal display.

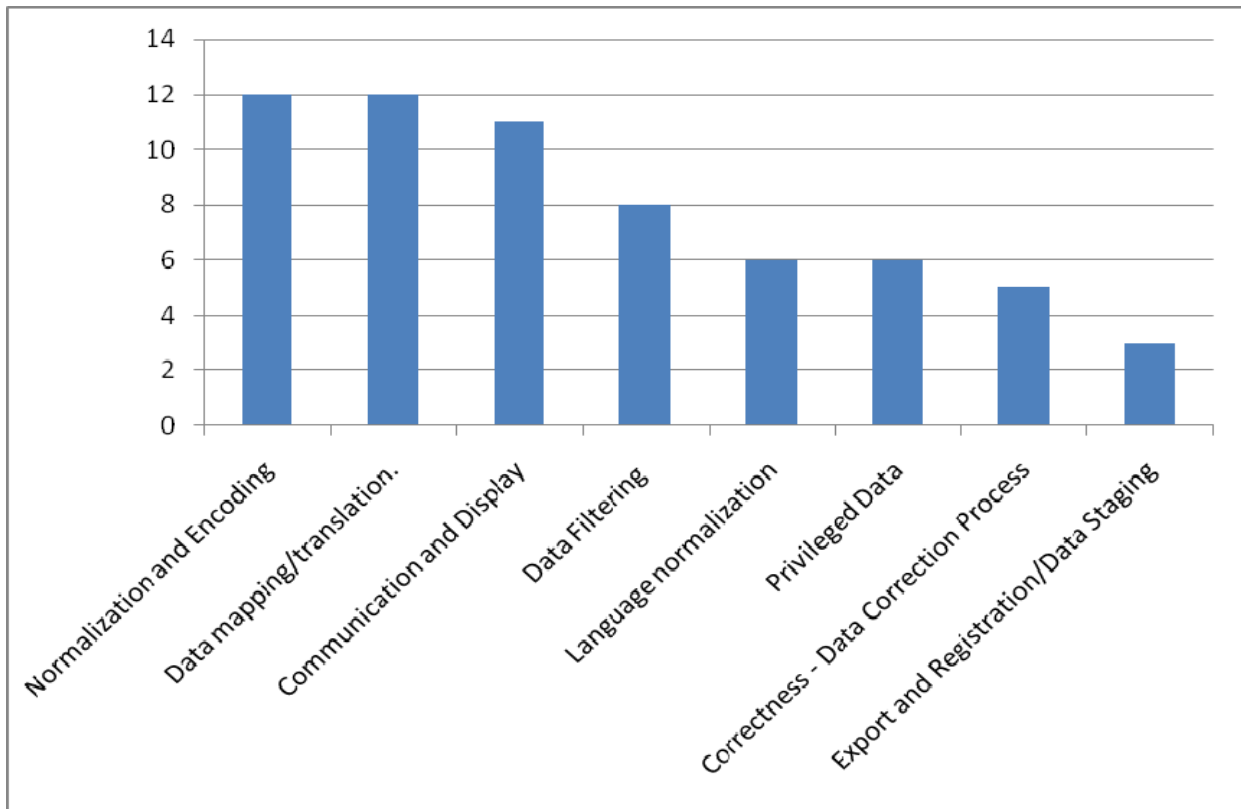


Figure 6. Data Management

Most of the respondents support the data standards of International Classification of Diseases Revision (ICD-9), Current Procedural Terminology 4th Edition (CPT-4), Logical Observation Identifiers Names and Codes (LOINC-1), and National Drug Code (NDC) (Figure 6). ICD-9 is a 5-digit code that identifies the illness, injury or disease. CPT-4 is a standard that describes the medical, surgical and diagnostic services provided by clinicians. LOINC-1 is a standard for

identifying laboratory observation values. Lab data is most often encoded with LOINC values for the test nomenclature and components, which would explain why these values are present in so many of the respondents' systems. NDC is used to identify drugs intended for human use. Data standards cited as not currently supported by the survey participants but planned for the future are SNOMED and NDC.

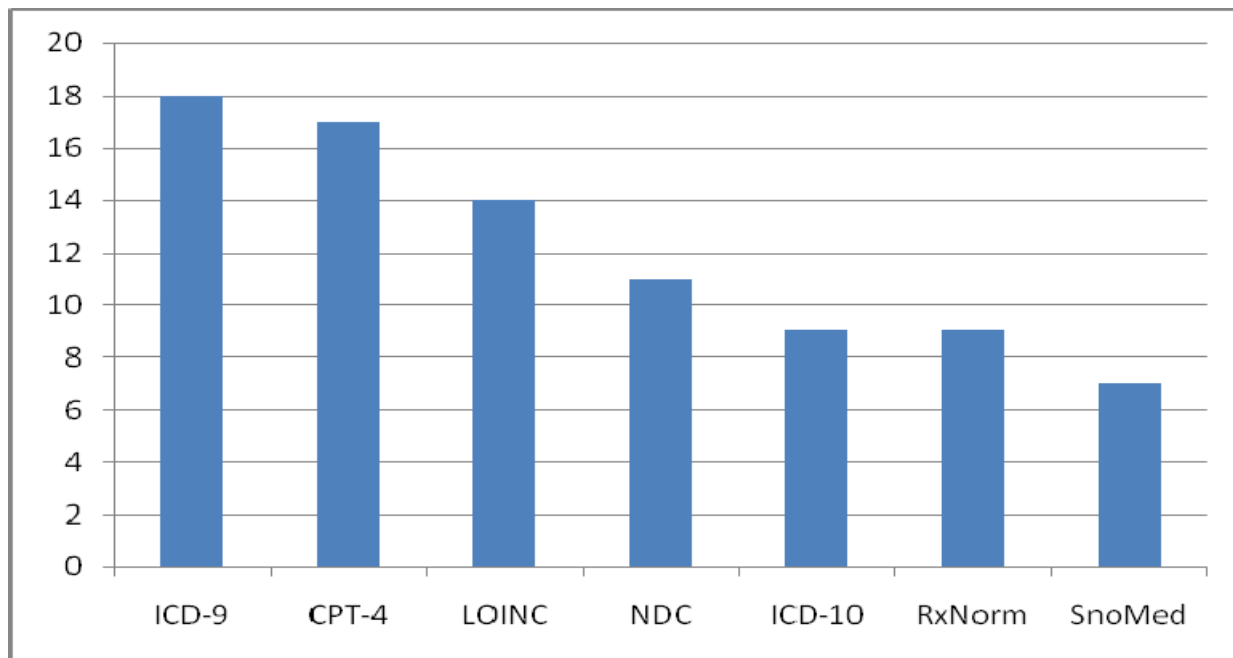


Figure 7. Data Standards

Data management in the healthcare setting is often supervised by individuals skilled in health information management (HIM). This is especially important for any data that is considered privileged or sensitive. Thirty-five percent (35%) of the respondents employ an HIM function for data quality and management. It is critical that all healthcare entities including HIEs obtain a comprehensive understanding of the federal and state laws that govern health data sharing and exchange.

Data Exchange

Survey Questions 33-39

Six (6) respondents indicated that they were exchanging data only in a pilot mode. The remaining participating organizations have been in operation for an average of 3.7 years with a span from less than one year to eleven (11) years. The date of the first actual data exchange by a respondent occurred in 1997. Twenty-five percent (25%) of the respondents had their first data exchange event occur in 2008. Bi-directional data exchanges occur in seventy-one percent (71%) of the respondents while twenty-nine percent (29%) indicated one-way data exchanges.

All of the organizations that are currently exchanging data one way indicated they will be moving to bi-directional exchange in the future.

While ninety-five percent (95%) of the HIEs indicated that the type of data being exchanged is clinical, an additional thirty-eight percent (38%) of the HIEs also exchange business/financial data. Data is exchanged between many different settings, but the most frequently cited exchanges by the participants are between inpatient, outpatient, and physician office settings. The types of data most often cited as being exchanged are lab results and prescriptions. Clinical patient notes and documentation are also cited as being exchanged between inpatient and outpatient settings. Registry and public health settings appear to primarily receive messaging/alerts and enrollment/eligibility from their HIEs. Other financial data cited as being exchanged by the participants includes enrollment/eligibility, claims/payments and reporting.

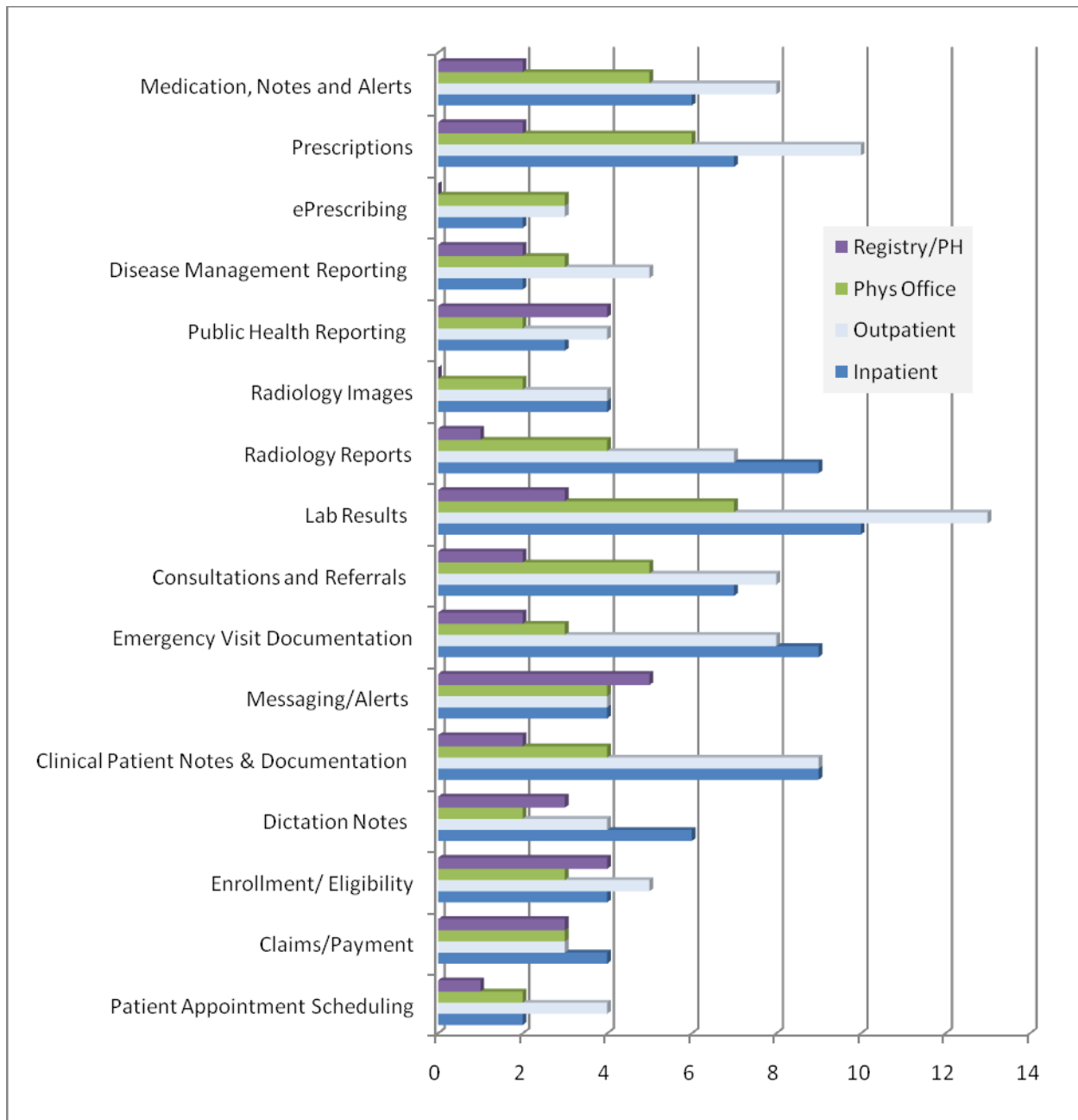


Figure 8. Data Exchange

Eighty percent (80%) of the participating HIEs measure their data exchange activity. Most of the respondents measure this activity through data transactions. Some of the respondents indicated the use of measurements such as the number of patients, number of views and number of unique users.

Privacy and Security

Survey Questions 45, 48, 62-65, 74

Information privacy and security is a cornerstone of any HIE organization. HIEs must instill trust and demonstrate that they are taking every possible precaution and safeguard with the data. Most all of the participating organizations cited all or a combination of the privacy and security strategies identified below as either deployed or being planned for deployment:

- HIPAA Compliance: While HIEs may not directly be covered entities under the HIPAA rules, many indicated conforming to HIPAA either voluntarily, or due to their business associate relationships with their constituent providers.
- Access Management: Access management is a function of both user authentication and authorization. Authorization may be further constrained based on the sensitivity and use of data.
- Role-Based Access: Role-based access uses the definition of roles to determine who is requesting the data and can also be used as a proxy for access control.
- Entity/Individual Authentication/Trust Model: This is a method of how user authentication is accomplished. Trust models and “chains of trust” are used where federated authentication is required.
- Auditing/Logs/Review: HIE entities activity logs are important for the tracking of access and to verify that the data use is for legitimate purposes. The logs are most useful within entities that have a routine process for log reviews and determination if any disclosure violations have occurred. All but two of the responses from the participants indicated that audit logs were part of the HIEs technical deployment.
- Health Information Security and Privacy Collaboration (HISPC): The HISPC project is tasked with the determination of appropriate privacy and security standards for HIE environments.

Consent

Consent is the general term used for the process of allowing patients to make their own determination regarding whether or not they want their data included in the exchange. There are two accepted models. “Opt-in” assumes that the patients’ data will not be included unless they specifically approve it. “Opt-out” assumes just the opposite; data will be included unless the patient specifically says otherwise. Sixty percent (60%) of the HIE respondents allow for one of these two models. The patient opt in/out choice can sometimes be further refined to provider, facility and/or data type, such as behavioral health or diagnosis (e.g., AIDS). The choice to opt in/out is available at the provider level for seven (7) of the respondents and at the facility level

for five (5) respondents. Only four (4) respondents indicated that the opt in/out choice is extended to the type of data (e.g. data sensitivity). Organizations that do not allow for opt in/out indicated that it was not relevant to their use cases (laboratory results delivery and treatment in the emergency department). One organization stated that opt in/out is not used because their technology is old.

Interoperability

Survey Questions 78-79, 80-81

Interoperability is critical to HIE organizations. As HIE activity grows in the industry, the breadth of data and users accessing the HIE will grow, placing new demands on the HIE entity. This growth will change how HIEs handle data exchange over time.

Electronic personal health records (ePHRs) are one application that may very quickly become a significant driving force within HIE entities. Personal health records (PHRs) are electronic medical records focused on individual patients. Seventy-nine percent (79%) of the survey respondents stated that they have considered how their HIE would integrate and interoperate with PHRs and other data banks. Some of the participants expressed plans to implement PHRs for patients with chronic diseases. All twenty-one survey participants indicated that they considered interoperation with PHRs and plan to incorporate PHRs into their HIE application in the future.

As health information exchange activity grows across the country, the ability of HIE entities to connect with other local HIE entities, state level exchanges and even the National Health Information Network (NHIN) will be critical. The NHIN is the nationwide network which will provide a secure, interoperable information infrastructure to connect providers, consumers and others involved in healthcare. Several of the survey participants are either participating in the NHIN or plan to “leverage the work being done by the other NHIN pilot participants who were awarded the Consumer Use Cases.” Eighty-five percent (85%) of the responding HIEs indicated that they have considered how they will interoperate with other HIE organizations at the state or federal level. Six (6) of the participants are or were involved in the NHIN trial implementations. Eight (8) other participants indicated that they are following nationally accepted standards and implementation guidelines (Healthcare Information Technology Standards Panel/Certification Commission for Healthcare Information Technology).

It is safe to conclude that all the survey participants exchanging data have done so through a concentrated effort within their own community or region. Those that are or have participated in the NHIN are looking ahead with technology that may become part of the interoperability that all HIEs will require for future data exchange with the NHIN. While a full-functioning nationwide

exchange is currently not in place, the HIEs in today's industry are providing a valuable and necessary service for their constituents.

Conclusion

The HIMSS HIE Common Practices Survey sought to understand HIE entities better through a survey regarding the organizational formation, structure and technical components. Trends were observed based on the responses to the survey from the participating HIEs.

During formation, most of the responding HIEs appeared to have the common purpose of being more efficient, improving patient care and reducing the rise of healthcare costs. The top three organizational start-up documents developed appeared to be capital budgets, business cases, and a three-year operating budget. The formation of an HIE entity appears to be most often a result of community involvement with a strong provider influence taking a leadership role. The uniqueness of resources, regions, and charters, however, drove the survey participants in different directions. Based on responses, the participating HIEs did not typically rely on existing HIE models or guidelines as the final model for their organization.

The HIE organizations that responded were found to be similar in many ways. Ninety percent (90%) of the HIEs are non-profit with sixty-seven percent (67%) of these non-profit organizations being 501(c)(3). Most of the participating HIEs have hospitals, primary care physicians and specialty care physicians as a part of the core stakeholder group through the start-up, transition and production stages. All of the respondents use a membership model for sustainable funding. However, sixty-one percent (61%) of the respondents expressed a dependency on grants and contracts to maintain long-term sustainability.

Trends were also observed based on the survey responses in the technical area. The architecture used by two-thirds of the respondents is hybrid, with one-third of the respondents indicating a centralized architecture. A hosted source, usually provided by the primary vendor, operated the data exchange activities for seventy-one percent (71%) of the respondents. Open source system-level products were used by sixty-seven percent (67%) of the respondents, but only ten percent appeared to use HIE application-level open source software.

There appears to be a commonality with data management across the participating HIE organizations. HL7 is used as the message standard by ninety percent (90%) of the survey participants. Data transformation primarily used "normalization and encoding" and "data mapping/translation." Most all of the participating HIEs currently support the data standards of ICD-9, CPT-4, LOINC-1 and NDC. Measurement of data exchange activity, usually by data transaction count, is done by eighty percent (80%) of the responding HIEs.

Privacy and security were observed to be very important to all the participants. All of the security strategies listed in the survey were identified as being used by most of the HIE respondents.

Interoperability appears to be a major concern of the HIE respondents. Seventy-nine percent (79%) of the respondents considered having personal health records and eighty-five percent (85%) considered interoperability with other HIE organizations at the state or federal level.

These trends suggest that HIEs may be more similar than different in many areas, which could be considered as some common practices across HIEs at this point in time. As the industry moves forward with information exchange initiatives including the engagement of new participants and experiencing heightened state-level and national focus, HIE practices will lead to different trends than what was observed in this survey. Future studies could focus on areas similar in nature to this survey in order to continue to learn from organizations conducting health information exchange and identify any future common practices and differences. The Task Force recommends that this survey, or one of a similar nature and complexity, be repeated in the future in order to assess the environmental state of the HIE industry and determine common and emerging trends in organizations and technologies.

Appendix A



HIMSS RHIO/HIE Technology Best Practices Task Force Survey

Primary Contact Information

1. Please provide the following information.

Organization Name

Primary Contact

Title

Organization URL

Address, City, State, Zip Code

Phone number

Email address

2. Is Clinical Data Exchange occurring in pilot mode only?

- Yes
- No

3. Would you like yourself and the organization you represent identified as survey participants in this study and resulting report?

- Yes
- No

Location

4. What is the primary office location? (City, State)

5. What is the geographic coverage of the RHIO/HIE?

(This identifies the state specific geographic region, community or federated of the state the entity's trading area supports)

Local Community

Region (across multiple states)

State or Areas within a specific state

Federated Locations (multiple independent locations not geographically based, i.e. HealthBridge)

RHIO/HIE Formation & Organizational Description

6. Please indicate the organization's initial purpose(s) and driver(s) to start the RHIO/HIE.

(Select **ALL** that apply)

- Improving of quality healthcare
- Improving patient safety
- State initiative or legislative mandate
- Governor's executive order
- Inefficiencies experienced by providers who need information to support patient care
- Rising healthcare costs
- Availability of Grant Funding
- Competition (get ours started before our competitors)

- Cooperative effort to provide an EHR to a community of physicians
- Reduction of paper
- Other

7. What is the date the organization was officially started?

8. What is the date of governance creation/bylaws/incorporation?

9. What is the organization type/status?

- Profit
- Not for profit

10. If not for profit, what is the type of not for profit?

11. Please provide a brief description of the organizational structure.

12. Prior to the organization's start-up, please indicate which of the following were completed.

(Select **ALL** that apply)

- Business case developed
- Return on Investment performed by initial funding stakeholders
- Plan in place for long-term viability of the organization
- Plan in place for sustained funding
- Start-up operating budget created
- 3-year operating budget created
- Start-up capital budget created
- 3-year capital budget created

13. What initial services were *planned* to be provided by the organization?

(Select **ALL** that apply)

- Data exchange/sharing
- Results Delivery
- EHR Services
- Alerts
- Registry
- Public Health Reporting
- Quality Indicator Reporting
- User Authentication & Authorization
- MPI Patient Locator Services
- ePrescribe
- Chronic Disease Management
- Other (give a brief example)

Initial & Sustaining Participants / Stakeholders

14. Please indicate all types of stakeholders who are Currently participating in your RHIO/HIE organization, were Initially Engaged and if they Provided any of the Start-up Funding.

Currently Engaged (In any capacity)	Initially Engaged?	Provided Start-up Funding?
<input type="checkbox"/> Hospitals	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Primary Care Physicians	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Specialty Care Physicians	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Ambulatory Care/Outpatient Clinics	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Nursing Home	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Rehabilitation Center or other Chronic care facility	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Behavioral or Mental Health	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Laboratories	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Radiology Centers	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Pharmacy (independent or hospital based)	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Community and/or Public Health Clinics	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Public Health Departments/CDC	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Private Payer/Health Plans	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Federal/State Plans (Medicare/Medicaid)	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Pharmacy Benefits Managers (PBMs)	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Employers or Healthcare Purchasers	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Software/Hardware Vendors	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Suppliers	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Quality Improvement Organizations	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Patient or Consumer Groups	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Other (please describe)	<input type="checkbox"/>	<input type="checkbox"/>

15. Were any stakeholder constituencies specifically excluded from participating?

- Yes
- No

16. If yes, please explain the reasoning used and indicate if they are still excluded.

If they are not still excluded, please also indicate how they are now participating.

Leading Sponsor (Convening Authority or Driver) Organization

17. Start-up Initiative: Choose the type of initiative that best describes how the RHIO/HIE was initiated or convened.

(Select Only **ONE**)

- One primary “key” provider
- One primary “key” payer/employer
- One primary “key” vendor/consultancy who acted to coalesce the community
- Community initiated (several providers &/or other interested parties)
- Outgrowth from another existing data sharing operation (e.g. registry)
- Community action group composed of consumers/patients
- Other (give a brief explanation)

18. Identify the *lead* organization(s) for the RHIO or HIE organization if there is a leading organization or group of organizations.

19. Does the organization use a participant agreement with the Stakeholders?

- Yes
- No

20. If yes, what are the agreement requirements for stakeholders?

21. Does the organization utilize a membership model?

- Yes
- No

22. If yes, give a brief description of the membership model.

23. Is the organization presently operating?

- Yes
- No

24. If no, briefly indicate the key factors that caused the organization to fail.

25. Management: Is the organization managed by a paid individual who is either part of the organization's staff or is a contractor?

- Yes
- No

26. Oversight: Is the organizational oversight (e.g. "board-level" direction) performed by individuals who are primarily from:

(Select Only **ONE**)

- Funding Organizations
- Participating Organizations
- Other Community Interest Group that may have funders, non-funding participants, and other interested parties

Sustaining Funding Sources & Uses

27. Sources: Identify the current sources of funding for your organization as appropriate.

(Select **ALL** that apply)

- In-Kind Resources
- Continuing financial contributions (donations, grants)
- Recurring subscription-based fee
- Recurring transaction-based fee
- Ongoing resource contributions from a related 3rd party (e.g., vendor)
- Grant or contract from Government
- Grant or contract from Non- Government organization (e.g., foundation)
- Grant or contract from Other:
- Cash loans or other valued resources which will have to be paid back
- Other

28. If grants and other beneficial funding were to be removed from the organization's sustained cash flow, how long would the organization survive?

(Number of months until cash reserves would be fully depleted)

29. Please indicate the approximate percentage of operational funding used for the following purposes.

(Total should equal **100%**)

- o Salaries/Wages/Benefits _____
 - o Consultants / contractors _____
 - o Vendors (support + implementation & ongoing staffing) _____
 - o ASP or outside service bureau fees _____
 - o Principal and Interest on loans being paid off _____
 - o Office materials & supplies _____
 - o Travel (include transportation, lodging, per Diems, etc.) _____
 - o Advertising & Marketing _____
 - o Trading partner site implementation costs paid by the RHIO/HIE _____
 - o Other _____
- 100%**

30. Did you pattern your organization's implementation model after another RHIO/HIE or another successful data sharing/exchange model?

- Yes
- No

31. Did you follow a pre-established implementation guide for creating your RHIO/HIE (e.g. eHI or Markle)?

- Yes
- No

[RHIO/HIE Organizational History](#)

32. Provide a brief overview of the RHIO/HIE.

Data Exchange Activities

33. What was the date of 1st actual data exchange in the organization?

34. What is the scope of current data exchange activity?

- One way
- Bi-directional

35. If One Way, is Bi-Directional data exchange planned?

- Yes
- No

36. What type of data is being exchanged?

- Business/Financial Data
- Clinical Data
- Other

37. Does the organization measure its data exchange activity?

- Yes
- No

38. If yes, by what criteria?

(e.g., number of transactions, number of patients, etc.)

39. Please identify the scope of the current data being exchanged.

Please mark the appropriate boxes.

Setting \ Data	Inpatient	Outpatient/Clinic	Physician Office Practice	Registry /Public Health	Payer	Government Reporting
Patient Appointment Scheduling						
Claims/Payment						
Enrollment/ Eligibility						
Dictation Notes						
Clinical Patient Notes & Documentation						
Messaging/Alerts						
Emergency Visit Documentation						
Consultations and Referrals						
Lab Results						
Radiology Reports						
Radiology Images						
Other Results Reporting						
Other Medical Specialty Documentation						
EMT / 1 st Responder Notes						
Public Health Reporting						
Quality Initiative Reporting						
Disease Management Reporting						
ePrescribing						
PHR /Patient reported data						
Medication, Notes and Alerts						
Prescriptions						
Other						

Technical Aspects of the Organization

40. If you prefer to complete the remaining portion of the survey with a telephone call, please indicate below.

- Yes, I would like to complete the remainder of the survey with a telephone call. Please contact me to schedule. If yes, you will be contacted
- No, I prefer to complete the survey online. If no, please continue with survey.

Overall Architecture and System Design

41. Did you consider system architecture before the HIE was organized?

- Yes
- No

42. What is the overall architecture of the HIE?

- Federated
- Centralized
- Other
- Not Applicable

43. Do the organization data exchange activities operate from a Hosted Site (Outsourced) or at your own facility?

- Outsourced
- Not Outsourced

44. If outsourced, please provide a brief description.

45. What Business Continuity features does your RHIO/HIE have?

(Select **ALL** that apply)

- Disaster Recovery Site
- Storage Area Network (SAN)
- Mirrored or RAID Disk Architecture
- Hot-Failover Servers
- Virtualized / High Availability Servers

46. Indicate the Architectural Elements Included in the HIE.

(Select **ALL** that apply)

- Central Registry of Participating Entities
- Central Registry of Users (centralized user authentication & authorization)
- Central Patient Index / MPI (central patient identity resolution)
- Record Locator Service
- Clinical Repository (clinical data on patients stored centrally)
- Transaction Logs (logs of who requested data and what data was provided)
- Portal for authorized viewing of data
- Document Registry (locator of documents in federated systems)
- Other
- N/A

47. Indicate the organization's network requirements to the end user.

(Select **ALL** that apply)

- Internet Access:
- Phone Line
- VPN
- Redundancy
- >56 Kbps Capacity

48. What are the Service Levels for the Design?

(Include **ALL** that apply)

Response times:

Support and Training:

Other:

49. Is SOA (service oriented architecture) used?

Yes

No

50. If yes, please provide a brief description.

51. If no, why not?

52. Are Open Source Software Products used to drive the HIE?

Yes

No

53. If yes, please provide a brief description of which products and which functions.

54. If no, why not?

55. Please provide the URL of a website or other location where we can find a high-level architecture diagram showing your technical architecture. (If none, indicate a person we can contact to obtain a diagram.)

56. Was the choice of technical architecture a result of the choice of vendor?

(In other words, the architecture is a result of which vendor was chosen to implement the HIE.)

Yes

No

57. If yes, which vendor?

Build or Buy

58. What was the strategy for organization?

Build

Buy

59. Why Build?

60. Why Buy?

Application Suite / Services Offered

61. Briefly describe the Software Application Suite and its functionality.

EMPI
Record Locator
CCR/CCD
Interfaces *to other systems (Lab, etc.)*
Portals
User Authentication & Authorization
Transaction Logging
Other

Security

62. Briefly explain the Security Strategy with the exchange of information in the organization.

(Include ALL that apply)

- HIPAA Compliance
- Access
- Role-based
- Encryption
- Entity/Individual Authentication/Trust Model
- Auditing/Logs/Review
- HISPC Standards
- Other

63. Does the organization allow for Patient Opt In/Out?

- Yes
- No

64. If yes, please provide a brief description for each of the following.

- By Provider
- By Facility
- By Data Type (Behavioral Health, AIDS)

65. If no, why not?

Data Management

66. What is the strategy for management of data within the organizational exchange? (Select ALL that apply) To include areas such as:

- Normalization and Encoding
- Language normalization
- Export and Registration of Data Objects/Data Staging
- Communication and Display
- Correctness – Data Correction Process
- Data Filtering
- Privileged Data
- Data mapping/translation.
- Other

67. Do you have a HIM role in managing/monitoring data?

- Yes
- No -- HIE may be just a technical exchange.

Standards

68. What are the Data Standards supported?

(Select ALL that apply)

- SnoMed
- LOINC
- NDC
- ICD-9
- ICD-10
- CPT-4
- RxNorm
- Other

69. What Data Standards not currently supported are planned for the future?

70. What are the Messaging Standards supported?

(Select ALL that apply)?

- HL7
- DICOM
- NCPDP
- X12
- Other

71. What Messaging Standards not currently supported are planned for the future?

72. Are there any other Standards that's use has been decided against by the organization?

- Yes
- No

73. If yes, please provide a brief explanation.

Pitfalls and Lessons Learned

74. Please provide a brief description of any pitfalls or lessons learned that may be helpful to others embarking on the establishment of RHIO/HIE organizations.

Suppliers

75. Please list below all major technology and supply vendors.

Vendor	Product /Service Provided	Purpose	Key reason selected	IHE profiles used

Benefits Realized

76. Are there any measures to determine ROI and/or benefits realized from the data exchange function?

- Yes
- No

77. If yes, please provide a brief description of the measurements and current results.

Alignment with other Regional, State and National HIE efforts

78. Have you considered how your HIE will interoperate with other HIE organizations at the state or Federal level?

- Yes
- No

79. If yes, please provide a brief description of your considerations.

(e.g. What changes will you have to make in your applications and services?)

80. Have you considered how interoperation with ePHRs and Data Banks will affect your HIE?

(i.e. Will you eventually allow individuals (patients) to access the HIE?)

- Yes
- No

81. If yes, please provide a brief description of your considerations.



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